Sleep Series for Individuals with 22q11.2 Differences

Parasomnias

Parasomnias are a collection of sleep disorders involving unintended behaviors or unwanted events during sleep. People with parasomnias may appear to be awake during those events, but they are in fact asleep and do not realize what they are doing. Although parasomnias can alarm parents, they can be managed, and most children grow out of them.

Risk Factors of Parasomnias

- Not getting enough sleep going to bed too late or waking too early
- Poor quality sleep or other sleep disorders
- Certain medical conditions (e.g. mental health problems) and medications
- Sleeping in an unfamiliar setting (e.g. travelling)
- Sleeping in a noisy or bright environment
- Family history of parasomnia

Types of Parasomnias

- Nightmares
- Sleep eating disorder
- Sleep hallucinations
- · Sleep paralysis
- · Sleep talking
- Sleep terrors
- · Sleep walking
- REM Sleep behavior disorder
- Exploding head syndrome
- · Confusional arousals
- Bedwetting

For descriptions of these parasomnias, please see sleepeducation.org/sleep-disorders

Parasomnias Common in Individuals with 22q Differences

There are multiple types of parasomnias (see yellow box on top right). The most common ones among children (especially younger ones) with 22q11.2 deletions and duplications are **sleep terrors**, **confusional arousal**, and **sleep walking**.



Sleep Terrors

Sleep terrors (night terrors) usually happen during stage N3 sleep in the first third of the night in children, and in any part of the sleep cycle in adults. People with sleep terrors wake up with intense fear but minimal memory of scary dreams. They will sit up, scream, move violently, and even run around. However, they are not awake, will not respond appropriately during the episodes, and will not remember what happened afterwards. Children with sleep terrors may also talk and walk in their sleep. Fortunately, sleep terrors usually go away by teenage years.



Confusional Arousals

Confusional arousals usually happen during stage N3 sleep in the first third of the night, but can also happen in any part of sleep or during naps. When people with confusional arousal wake up, they think and act strangely. During these 5 to 15 minutes, they may stare without focusing, talk bluntly or slowly, act aggressively, and struggle to remember things. Children with confusional arousals usually grow out of them after age 5 but may sleepwalk when they are teens.



Sleep Walking

Sleep walking (somnambulism) most often happen during the first third of the night's sleep but can happen during any other long sleep periods, including naps. When people sleepwalk, their eyes are open and look confused, but they are not awake. They may do things (e.g. eating) that are normally done during the day but not at night, and they may do things at the wrong place (e.g. go pee in a garbage bin). They may walk back to bed or go out of the house. Children who sleep walk may also talk in their sleep and have sleep terrors and have a history of confusional arousal. Sleepwalking is more common in children than in adults.

Sleep Series for Individuals with 22q11.2 Differences

Parasomnias (continued)

Managing Parasomnias

Although parasomnias usually end on their own, they can be distressing for parents and family members. Here are some management strategies.

(1) Decrease the frequency of parasomnias

Parasomnias occur more when people don't have enough sleep or have disrupted sleep. To minimize parasomnias:

- Get enough sleep by going to sleep earlier or waking up later
- Have a consistent sleep routine (both time and location) as much as possible, even during weekends and holidays
- Treat conditions that disrupt sleep. E.g. sleep breathing problems (sleep apnea) and other medical conditions

(2) Ensure the person will be safe when parasomnias happen

The person who is sleepwalking cannot recognize hazards, so parents and family members need to be prepared in advance.

- Let the person sleep on a low bed or a mattress on the floor, and not on the top bunk.
- Remove tripping hazards every evening before sleep
- Secure windows and doors so that the person who sleepwalks cannot get out of the house. However, make sure the family can still escape in the event of an emergency.
- Set up a **bell or alarm** that will alert family members when the person has left the room. This can be as simple as a bell on the door knob or as sophisticated as a sensor that beeps when the door opens.

(3) Do not wake the person in a parasomnia episode

- Waking the person who is experiencing sleep terror and confusional arousal will likely make the episode last longer and make the person more agitated. Let the episode finish on its own.
- If the person is sleepwalking calmly, gently guide him/her back to bed. If he/she refuses to be guided, let the episode finish on its own.

(4) Do not talk about the episode with the person affected

- The person will <u>not</u> remember having a parasomnia episode.
- Discussing the parasomnia episode while the person affected is awake will make him/her fearful of having another episode. This will decrease the amount of sleep, thus increasing the frequency of episodes.

(5) Inform others who will take care of your child

Babysitters, parents of friends (for sleepovers), camp counsellors etc.
need to know the points mentioned above. Feel free to give them a copy of this information sheet.

Diagnosing Parasomnias

Parents of children who have parasomnia(s) can keep a record of the episodes as it will help medical providers with the diagnosis. Include:

- Sleep time
- Time of episode
- · What happened
- · Wake time

Medical providers may take the medical history of the patient and request a sleep study (<u>Polysomnography</u>) before providing a diagnosis.

Treating Parasomnias

Increasing the amount of good quality sleep makes a big difference in decreasing parasomnias. In severe cases, medications and cognitive behavioral therapies may be helpful.

Resources

- Parasomnias Cleveland Clinic
- Sleep Terrors (Night Terrors) | Sleepwalking – Mayo Clinic
- <u>Understanding Parasomnias</u> American Academy of Sleep Medicine (AASM)
- Sleep Disorders (Multiple topics) Sleepeducation.org by AASM
- Sleep patterns and problems among children with 22q11 deletion syndrome – 2020
- Sleep profiles in children with 22q deletion syndrome: a study of 100 consecutive children seen in a multidisciplinary clinic – 2023
- Updated clinical practice recommendations for managing [children | adults] with 22q11.2 deletion syndrome – 2023

Illustrations from Freepik.com and emojipedia.org



The mission of the <u>International 22q11.2 Foundation</u> is to improve the quality of life for individuals affected by chromosome 22q11.2 differences through family and professional partnerships.

This information is brought to you by the Foundation for educational purposes only. It is <u>not</u> intended to be taken as medical advice. If you have concerns, please talk to your healthcare provider.